

# Open Research Online

---

The Open University's repository of research publications and other research outputs

## Showing how they feel: the emotional reflexivity of people with dementia

### Journal Item

#### How to cite:

Boyle, Geraldine and Warren, Lorna (2017). Showing how they feel: the emotional reflexivity of people with dementia. *Families, Relationships and Societies*, 6(1) pp. 3–19.

For guidance on citations see [FAQs](#).

© 2017 Policy Press



<https://creativecommons.org/licenses/by/4.0/>

Version: Version of Record

Link(s) to article on publisher's website:

<http://dx.doi.org/doi:10.1332/204674315X14328175376100>

---

Copyright and Moral Rights for the articles on this site are retained by the individual authors and/or other copyright owners. For more information on Open Research Online's data [policy](#) on reuse of materials please consult the policies page.

---

[oro.open.ac.uk](http://oro.open.ac.uk)



---

## research

---

# Showing how they feel: the emotional reflexivity of people with dementia

Geraldine Boyle, The Open University, UK  
[geraldine.boyle@open.ac.uk](mailto:geraldine.boyle@open.ac.uk)

Lorna Warren, University of Sheffield, UK  
[l.warren@sheffield.ac.uk](mailto:l.warren@sheffield.ac.uk)

This article explores whether people with dementia demonstrate emotional reflexivity within their personal relationships. Previous research has suggested that they may lose their capacity for reflection as the disease progresses. In turn, it has also been assumed that they lack the reflexive abilities necessary to exercise agency within their daily lives. The authors draw on findings from a qualitative study of everyday decision-making by people with dementia and their spouses undertaken in England. The sample consisted of 21 couples, but to enable emotional reflexivity to be examined in depth, this article focuses on the emotional communication of six people with more advanced dementia. The research found that even when their abilities for deliberation, discourse and social interaction were limited, they could nonetheless demonstrate emotional reflexivity. As they also exhibited a capacity for imaginative agency, this suggests that intersubjectivity can be preserved in dementia even when social skills are apparently lost.

**key words** agency • reflexivity • emotions • dementia • social relationships

---

## Introduction

### *The 'awareness' of people with dementia*

Cognitive psychology has narrowly defined awareness in people with dementia in terms of disease-related perceptions, such as loss of functional ability and performance (Aalten et al, 2005; Clare et al, 2011). Whereas neuropsychological research has focused on identifying the factors that influence 'unawareness', phenomenological research has explored when awareness may be retained (Aalten et al, 2005; Clare et al, 2008). Yet, while some research has shifted the focus from the disease to how self-identity is maintained (Clare, 2003), awareness remains narrowly conceptualised in terms of the impact of dementia on individual psychology. Although it had been assumed that awareness declines with increasing cognitive impairment (Woods and Pratt, 2005), more recent research has shown evidence of retained awareness in people

with moderate to severe dementia (Clare et al, 2008). However, the latter study was not able to inform on whether people with more advanced dementia retain broader capacities for reflection and reflexivity and can therefore use these abilities to exercise relational agency, that is, maintain a social self rather than a subjective self (Burkitt, 2008). In addition, since Clare et al's study sample was limited to people who could communicate verbally, their research could not provide evidence on how people with dementia might demonstrate emotional reflexivity.

As previous research into people with dementia has centred on self-identity and subjectivity, this has led to a neglect of their capacity for intersubjectivity (Robinson et al, 2005; Caddell and Clare, 2010). Yet, it is important to determine whether people with dementia demonstrate not just a subjective sense of being, but also an understanding of their relational selves, rooted in family and community life. Although previous research has not systematically explored whether people with dementia can manifest a social self, Sabat (2002) suggested that people with moderate to severe dementia can display social roles and personae, but that this relies on the acknowledgement of others. However, his findings were based on the conversation analysis of a woman able to participate in an in-depth interview.

This article considers whether people with more advanced dementia who lack decision-making capacity and speech can nonetheless view situations intersubjectively, engage relationally and subtly exercise influence within their relationships. It discusses to what extent the people with more advanced dementia who participated in the study used their emotions to form judgements about their interpersonal situations and to *respond* relationally, that is, with regard for their social bonds and (inter)dependencies. Whereas the concept of 'personal agency' is over-individualistic, a relational approach acknowledges how agency manifests itself, and is negotiated, within relationships of care and mutual dependence (Mackenzie and Stoljar, 2000; Hemmings and Treacher Kabesh, 2013). As the focus of this article is on the emotional reflexivity of people with more advanced dementia and their potential for agency, there is insufficient scope for examining the relational agency exercised by the couple as a whole (discussed in previous papers: Boyle, 2013a; 2013b, 2013c, 2014a). Instead, the article explores whether their emotional reflexivity shows an enduring recognition of their embeddedness within social relationships and their need for relational engagement and status, but also some understanding of the commitments and interests of others.

The dominance of the cognitive perspective in existing research reflects a divided view of the self whereby rational and emotional selves are viewed as superior and inferior entities (Burkitt, 2008). As rationality is deemed to be impaired in dementia (Brock, 1993), a loss of the sense of self is assumed to entail. Yet, since the cognitive model disregards the relational self, the potential of the person with dementia to demonstrate nuanced capacity to perceive, judge and subtly influence intimate relationships is also discounted. In other words, since the focus is on assessing individual cognitive impairment, whether the person retains emotional and relational abilities and a potential for emotional reflexivity is not considered. In particular, people who experience significant cognitive impairment such that they lack decision-making capacity and deliberative agency are assumed to lack reflective abilities more generally. Yet, adopting a socioemotional conception of the self would enable the reflexive capacity of people with dementia to be more readily recognised. As symbolic interactionism has shown, the social self is actively constructed and maintained via social interaction whereby meaning making is an emotional, not just

a cognitive, process (Fields et al, 2006). Correspondingly, reflection involves not just reasoning but also feeling and imagination (Burkitt, 2014). Likewise, emotion involves some capacity for reasoning (Smith, 2002). However, previous research has viewed the subjective self in dementia either as a cognitive construct that diminishes as cognitive abilities decline or as ‘embodied’ – but still disconnected – selfhood (Kontos, 2004; Caddell and Clare, 2010). Yet, a more rounded concept of the *social* self allows for the possibility that it endures despite cognitive impairment and manifests itself via socioemotional (including embodied) reflexivity.

### *From awareness to reflexivity*

As self-reflection is ‘the ordinary, everyday ways people reflect on themselves and their actions’ (Burkitt, 2012: 459), awareness therefore constitutes an example of reflection, but within a very limited context. Self-reflection is, in turn, the basis for reflexivity (Burkitt, 2012). Whereas Giddens (1991) narrowly conceptualised reflexivity as an individualistic reasoning process, Farrugia (2013: 12) cautioned that it cannot be reduced to ‘cognitive rationality’. Instead, Burkitt (2012) suggested that reflexivity is relational, dialogical and emotionally driven. In particular, reflexivity requires that we interpret our own and other people’s emotions (Holmes, 2010). Although Archer (2003) concluded that our ‘internal conversations’ point to distinctive modes of reflexivity that are indicative of rational agency, she did not explore in any depth the role of emotional relations in informing reflexivity. Indeed, she perceived that affect can be a barrier to effective reflexivity. On the contrary, however, our emotions convey our personal meanings and values and are a key means by which we understand our relationships with others (Sullivan and McCarthy, 2004).

### *Emotional reflexivity*

Although reflexivity necessitates that we engage in dialogue with ourselves and others (Sullivan, 2012), emotional reflexivity requires that we hold ‘real and imagined dialogue with what others think, do and *feel*’ (Holmes, 2010: 147, emphasis added). In turn, our emotions are felt and expressed through feelings, thoughts, talk and embodied communication (Holmes, 2010). While Kontos (2004) suggested that the embodied actions of residents with moderate to severe dementia demonstrated their selfhood, she attributed this to pre-reflective and primordial experience. Yet, emotional communication – whether via emotions, speech or actions – may indicate reflexive ability. Indeed, whereas agency theory privileges linguistic dialogue (Madhok, 2013), an emotional perspective recognises the importance of *emotional* dialogue. As ‘reflexivity’ is a more expansive concept that allows for the relational agency of people with dementia to be envisaged, it is a more fruitful basis for inquiry than the concept of ‘awareness’.

While Giddens (1991) suggested that agency involves the individual acting reflexively in order to achieve self-transformation, his model of ‘disconnected autonomy’ disregards its collective nature (Holmes, 2004). As Giddens’ concept of ‘agency’ also tends to portray individuals as omnipotent, it sets an unachievable standard, particularly for people with dementia (Hemmings and Treacher Kabesh, 2013). Rather than viewing reflexivity as a process of using knowledge to initiate social action (Giddens, 1984), a more grounded concept – relating to when people

act to influence their own personal circumstances – enables the potential agency of people with dementia to be considered, particularly their efforts to maintain intimate relationships (Madhok et al, 2013). However, as agency theory prioritises physical action (Velleman, 2000), this poses a barrier for people with dementia who may lack functional abilities. Consequently, the research presented in this article explored whether people with dementia might alternatively demonstrate agency via emotional action.

As cognitively disabled people provide an important case study of how reflexivity and agency might be demonstrated relationally and emotionally when reasoning is experienced as somewhat challenging, this article explores whether they demonstrate emotional reflexivity within their personal relationships. A sociological study enabled the relational self to be examined, especially in more advanced dementia and when language was limited. In particular, consideration is given to whether people who lack the practical abilities for social interaction can nonetheless remain emotionally engaged in social relations (albeit at an interior or imaginary level), for example via internal dialogue manifested in their personal monologues. Findings are drawn from an ESRC-funded study (Economic and Social Research Council) of everyday decision-making by people with dementia and their spouses, which aimed to identify the role of social factors in influencing their involvement in decisions. Whereas previous papers have examined the deliberative and embodied agency of people with dementia (eg, Boyle, 2014b), this article explores emotional reflexivity and potential agency in people with more advanced dementia (albeit often in embodied forms). As there has been a lack of empirical research into the emotionalisation of reflexivity (Holmes, 2010), this study makes a novel contribution to agency theory in relation to how such reflexivity can inform agency.

## Methods

An intensive qualitative methodology (see Denzin, 1970) was used to examine everyday decision-making processes by 21 people with dementia and their spouses living at home. Ethnographic and creative methods were employed, including participant observation and interviews (Hammersley and Atkinson, 2007; Mason and Dale, 2011). To enable the emotional reflexivity of people with dementia to be explored in depth, this analysis focuses on a subgroup of six people with more advanced dementia who usually had significantly impaired speech.

The study was undertaken in a local authority area in the North of England. Ethical approval was obtained from the national Social Care Research Ethics Committee. The fieldwork was undertaken over at least four home visits and each couple was observed going about their usual daily routines, in order to observe decision-making directly. Some observations were undertaken at home; others took place elsewhere, such as in a cafe or supermarket. An initial home visit and prior attendance at wellbeing cafes were helpful in making the first author and the research assistant familiar to the people with dementia, gaining their trust and enabling us to learn about each couple's daily routines. The cafes were informal events held in community centres, which provided opportunities for social interaction for people with dementia and their carers (Miesen and Jones, 2004).

A person-centred approach was used to informally assess the capacity of people with dementia to decide to take part in the study, as per the Mental Capacity Act

2005 in England and Wales. The severity of dementia was informally assessed – for example based on abilities to undertake activities of daily living – except where more definitive information was provided by a spouse (eg, information obtained via a memory assessment clinic). The assessments were broadly compared with the Clinical Dementia Rating scale (Hughes et al, 1982; Marin et al, 2001). Whereas semi-structured interviews were often undertaken with each partner, brief, unstructured and conversational-type interviews were carried out with five of the six people who had more advanced dementia. As an open-ended approach was too challenging, instead, these interviews incorporated closed questions or topics on key themes (such as their likes and dislikes), in order to explore their agreement or disagreement (Acton et al, 2007).

Photographs of the couples (including social activities undertaken during observations) were used as visual and memory aids throughout the fieldwork (Harper, 2002). Where they had speech difficulties, individuals' non-verbal communication – such as facial expressions or body movements – was observed (Mayhew et al, 2001). An 'interaction' method was employed to facilitate one woman's engagement and communication when it was not possible to interview her (see Grove et al, 1999). More specifically, the first author spent time with her on a one-to-one basis, used sensory aids (such as musical instruments) to stimulate her engagement, listened attentively to her speech and observed her non-verbal expressions.

### *Recruitment*

The couples were recruited via wellbeing cafes, support groups and day centres run by voluntary and statutory organisations. Theoretical sampling was used to recruit a diverse range of couples, including ensuring variation in the communication and cognitive abilities of people with dementia. The couples were eligible to participate if they were co-resident, one spouse had been diagnosed with dementia and both spouses were willing to take part. Couples were excluded where the partner had only recently been diagnosed (within the previous six months), to allow time for adjustment. The combined terms of memory problems and dementia were used to allow participants to determine their preferred terminology, on the basis that some people may not have accepted the diagnosis (Langdon et al, 2007).

Both spouses were asked to complete written consent forms or, alternatively, people with dementia gave verbal consent. Where they did not have the capacity to consent, in accordance with the Mental Capacity Act 2005, their spouses were consulted as to whether they would have wanted to participate and if they were happy for them to take part. However, throughout the fieldwork, the researchers were sensitive to any indicators of discomfort or undue anxiety from the people with dementia. The fieldwork was undertaken between June 2010 and May 2011. The interviews were digitally recorded and transcribed verbatim; fieldwork notes were recorded throughout.

### *Sample characteristics*

Twenty-one married couples took part, including 12 women and nine men with dementia (mainly over 65 years of age). The majority of the sample appeared to have mild or mild-to-moderate dementia (15 out of 21). However, this article focuses on the four women and two men who appeared to have moderate or moderate-to-severe

dementia and had been diagnosed for between three and 12 years. Most of them lacked the capacity to consent to taking part in the research (five out of six) and had significantly impaired speech (four out of six). Their ages ranged from early sixties to late eighties and they had been married for between 40 and 60 years. Whereas the overall study included one South Asian couple, the subgroup were all White British.

### *Data analysis*

Thematic data analysis was undertaken manually. The analysis was guided by key theoretical concepts – particularly relational reflexivity and emotional dialogue – but was also informed by participants’ meanings emerging from the analytical process. The data from each person with dementia (interview, observation and non-verbal) were explored in an integrated way (O’Cathain, 2010). As well as textual analysis, the audio-recordings were carefully listened to for evidence of speech patterns and tone of voice that might inform on emotional reflexivity (Kitzinger, 2000). For example, the analysis identified when self-references or affirmations were evident in talk or when the tone indicated emotional expressions or mood changes (such as annoyance or joy). An interpretative approach was particularly important for discerning meaning in the non-verbal communication of the people with dementia (Grove et al, 1999).

In order to identify whether they demonstrated emotional reflexivity, the analysis focused primarily on the data obtained directly from the people with dementia themselves. The authors examined what emotions they expressed and if they imagined other people’s emotions, whether they could interpret their own and other people’s emotions and whether they used these interpretations to inform their concerns (Holmes, 2010; Burkitt, 2012). Whereas the literature often regards the perspectives of people with dementia and their spouses as equivalent, the approach adopted in this study was to recognise the distinctive identity of each spouse – albeit the couple identity was also explored – and to enable the perspective of people with more advanced dementia to be examined in depth. The spouses’ knowledge of their partners’ personalities, habituated and changing routines and patterns of communication informed the researchers’ interpretations. However, in order to respect the equality of each partner and the trust accorded to us by the people with dementia, their spouses’ accounts were not used to ‘test’ the veracity of their standpoint. Instead, it was recognised that each partner had their own perspective, which often corresponded with the couple perspective, but might also diverge, and which could be influenced by the relationship to the illness (whether lived or observed).

The various sources (such as observations or interviews) and types of evidence (speech and non-verbal data) were corroborated in order to verify the accuracy of our interpretations. In addition, these were often checked at the time of the fieldwork, for example by rephrasing a statement to clarify understanding. To ensure that the participants’ interpretations informed our analysis, they were given the opportunity to clarify key issues, although this was not feasible for some people with dementia. While clearly ‘knowing’ the meanings of people with dementia can be a challenge (Nystrom and Lauritzen, 2005), the following facilitated more informed interpretations:

- developing a more intimate knowledge of them over multiple visits;
- clarifying their views and feelings;



- contextualising their expressions;
- exploring congruence between their verbal and non-verbal communication;
- examining spouses' insights.

## Findings

### *Expressing emotion*

Gavin<sup>1</sup> did not talk much – although this was partly due to impaired speech (related to his dementia), it also appeared that he was not very keen on conversation. Accordingly, he often responded to questions or prompts by saying: “I don’t know.” As his talk did not reveal much, we as researchers had to rely more on his emotions for clues to his views and feelings. We were particularly attentive to his tone of voice, as his facial expressions and body movements were not very informative either. Whereas an indifferent or negative tone suggested a lack of interest in a topic, a more emphatic tone indicated when he felt quite favourably about an issue. For example, he and his wife, Claire, attended church regularly, as she highlighted in her interview that she was strongly religious. When asked if he liked going to church, he seemed unwilling to reveal his feelings – “I don’t know to be honest” – but his flat tone suggested a lack of interest. As he explained that “Claire wants to [go] regular”, this suggested that it was mainly his wife’s fervour that prompted their frequent attendance. In contrast, he appeared to enjoy the social aspects of church-going. More specifically, when asked if he knew many people at church, his response was quite emphatic and enthusiastic: “Oh, yeah, I know plenty people.” Similarly, Claire explained that Gavin had been a very sociable man prior to the dementia, for example through involvement in sporting activities. Although Gavin said little about his ongoing marital relationship, his affection for Claire was conveyed in an embodied form, rather than articulated directly. More specifically, when the research assistant showed him photographs of the couple (taken on a previous visit), he readily identified them: “That’s Claire, that’s me.” As he pointed to his wife first and also used an upbeat tone, this indicated his retained awareness of their marital relationship and suggested an enduring fondness for her. Similarly, when asked if he had initially met (‘spotted’) his wife at a dance, he reminisced with evident pride on his determination then: “I didn’t spot her [pause] I took her.”

Derek, who had dementia, talked quite readily and could identify his leisure interests, such as gardening and reading, although Julie, his wife, indicated in her interview that he was no longer able to undertake gardening tasks. As Derek mentioned that he enjoyed reading books about history but also “naughty ladies and so forth”, this reflected his dry but also slightly ‘wicked’ sense of humour. He was quite forthcoming about his marital relationship: “Um [pause], I live here happily enough, with the wife.... And, um, I don’t think I’d be very pleased without one!” However, it appeared that Derek felt somewhat confined, as he rarely went out, the couple received few visitors and he spent quite a lot of time on his own. Accordingly, he seemed preoccupied with his physical surroundings and with getting some exercise. As he had previously visited his daughter on a regular basis but stayed at home now instead (his wife said he could no longer drive), implicitly, it appeared that he missed these visits: “Yeah, these things, I just let, let all these things flow by and, um, and what I have to do is, is stay here and get some exercise, and that’s all.” As Derek mentioned the importance



of exercise three times in his interview, this suggested that he felt somewhat inactive. Similarly, during the observation visit, he described himself as “bone idle”. Notably, he expressed these feelings more via embodied emotions, rather than explicit articulation, for example when he gestured eagerly to show how a different room layout would enable him to exercise. However, Julie felt that he was quite contented sitting at home: “He is very happy sitting here ... he doesn’t want to go out, no.” As she had commented during her interview that Derek had “been a loner” and that they had always had quite separate social lives – “[we] always tended to go [our] own ways” – this pattern was habituated within their marriage.

Trevor said that his wife, Mary, who had dementia, had “always liked meeting people”. Her sociable nature was evident during the fieldwork as she was very chatty and cheerful. Correspondingly, she commented: “I like people. I love people.” In contrast, Dennis said that his wife, Grace, who had dementia, became anxious whenever there were visitors. Indeed, her anxiety was noticeable during our initial home visit, for example via her restless demeanour and her visual pattern of looking quizzically at us and then looking enquiringly to her husband, but also when she asked who we were and why we were there. Although anxiety around strangers is common in people with dementia (Miesen, 1992), as Dennis said he had pursued his own leisure interests earlier in their marriage and his wife had been “reserved”, she had always been somewhat socially detached. Nonetheless, Grace became visibly more relaxed and somewhat more socially interactive as we became more familiar to her. For example, when the first author subsequently met the couple at a wellbeing cafe, Grace smiled and made a little exclamation, indicating that she recognised me and was pleased to see me, although she could not recall my name.

As Grace was very critical and disparaging of herself – frequently apologising to us for her perceived limitations – this pointed to a low sense of self-worth. For example, she often referred to herself as “silly” or “I’m so stupid”. However, her poor self-concept was not simply the result of the onset of her dementia as her husband said that she used to complain (earlier in their marriage) that he talked down to her, which he admitted was probably true. As Dennis had attended a grammar school (but she had not), he felt that she lacked the ability to understand him: “I’m not trying to be snobby.... But she couldn’t understand many of the words I used.... And she’d say to me: ‘I don’t know what you’re talking about.’” Consequently, her sense of self was not simply challenged by her illness but had already been undermined during the couple’s relationship. More specifically, our ‘self-feeling’ is influenced by how we imagine others judge us (Cooley, 1922). Indeed, as Dennis revealed during his interview that he had had an affair during their marriage, which his wife was fully aware of, this may also have contributed to her diminished sense of self: “Well, I’ve been a bit of a phil- philanderer.”

### *Imagining and interpreting emotion*

Mary who was married to Trevor, was quite frank about how she felt and her feelings also conveyed how she made social judgements. For example, when the research assistant explained that we worked in a university, she joked sarcastically about our perceived social position and implied that we had an exaggerated sense of our own status!: “Oh, you’re posh aren’t you, bloody hell.... Hey, you think you’re somebody don’t you?” Mary also spoke openly about her and her husband’s love for each other.

At the observation visit, she asked Trevor: “We love each other don’t we?”, whereupon he affirmed: “Course we do.” As well as being aware of her own feelings, Mary was also sensitive to other people’s feelings: “I don’t like hurting or upsetting people if I can help it.” In setting a moral standard for her own behaviour, she similarly applied this benchmark to others: “I only like people that I like to know that they’re kind, and that they’re kind to other people.” Correspondingly, she judged that Trevor was “kind and gentle and loving”. Rather than being guided by religion, Mary adhered more to a moral code of conduct: “[I] don’t go to church, I’m guilty of it, I should go really, but I try to be good.” Accordingly, she used her own and other people’s emotions to make ethical judgements and direct her relationships.

Initially, Marion who was married to Joseph, was not very receptive to the researchers – particularly as she felt that she did not have memory problems – and her unfriendly body language indicated that she did not necessarily welcome our presence. For example, her tone of voice was quite negative, her posture was rigid and her facial expressions were surly. She was irritable at times with Joseph, particularly when he commented negatively on her memory problems. He frequently mentioned her apparent lack of understanding and she glared at him and said “what?” quite irately, which seemed to mean “what are you saying about me?”, ironically evincing her comprehension. At a subsequent visit, her mood was more upbeat, for example she smiled and laughed frequently. At times, she laughed in response to tangible aspects of her social environment, for example when she discerned how her dog enjoyed being dried with a hairdryer by her husband (which he often did when they had been for a walk together). Yet, in other instances, her joy appeared to be triggered by her internal world, for example a reaction to positive thoughts or memories. In particular, during her interview, her broad smiles were seemingly prompted at times – not by the topics explored or the interaction – but by her own thoughts. As Marion had limited ability for social interaction and no longer enjoyed seeing friends – partly because her husband said (in his interview) that she was embarrassed about her speech impairment – it may be that her inner social world substituted, to some extent, for the contraction of her social life. However, irrespective of her loss of language and some social skills, Marion demonstrated that she was attuned to other people’s emotions and could respond sensitively to them. For example, during the observation visit, when the couple’s dog grabbed a chocolate bar out of her hand, the research assistant pointed this out to the husband-carer, perceiving that Marion was unable to judge and rectify the situation herself. On the contrary, however, Marion immediately intercepted, assuring her “not to worry” as this happened regularly. Thus, Marion not only discerned the research assistant’s concern on her behalf but, ironically, sought to relieve *her* anxiety. Irrespective of her cognitive impairment, Marion could therefore recognise the emotional reflexivity of others *and* demonstrate such reflexivity herself.

Emily had very limited ability for social interaction or conversation, for example she often communicated via utterances that did not have any evident meaning. During the consent visit, although Ken, her husband, had invited her to join us in the kitchen (where they frequently sat together), she chose to remain alone in the living room or to walk continuously between the two rooms. While Emily could not articulate how she felt about the presence of relative strangers, her movements conveyed her feelings, specifically her guardedness around unfamiliar people. However, during the first author’s subsequent one-to-one ‘interaction’ with Emily, it was noticeable that she remained in the living room even after I had joined her – albeit still walking

constantly – which indicated that she was comfortable with my presence and perhaps glad of the company. Similarly, while Emily had otherwise shown little awareness of my presence at the beginning of our ‘interaction’, towards the end when I explained that I was planning to go, her tone of voice became noticeably raised (although her utterances were unclear), which suggested that she had become accustomed to my presence and was reacting to my departure.

Although Emily lacked the ability to engage in conversation, her ‘monologue’ revealed that she maintained an internal dialogue with one or more other people who were notably absent, since her remarks did not seem to be directed to the first author but were instead addressed at people who were very familiar to her. More specifically, her dialogue demonstrated that she visualised others, imagined how they were feeling, contemplated her future actions and responded emotionally. For example, she enquired about the welfare of others – “are you all right?” – and sought to reassure them: “oh, don’t worry”. In turn, she directed affirmations to them: “I know love.” In addition, she apparently cajoled and even chastised herself: “Ah, you bloody well. Oh, I can’t do it ---- [own name] [inaudible]. You have to, have to [inaudible]....” Thus, her emotions showed how she was self-revelatory but also ‘self-interpreting and self-reactive’ (Denzin, 1984; Sugarman and Martin, 2011: 285). As Emily referred to herself in the first *and* second persons, this pointed to both a subjective sense of self and an awareness of herself as socially situated. Although Small et al (1998) suggested that people with advanced dementia may over-rely on first-person pronouns because of declining vocabulary, they acknowledged that their use of second- and third-person pronouns shows a recognition of their social world. Notably, Emily also considered reprimanding a man for a perceived misdemeanour, possibly her husband for leaving her alone in the company of the first author who was a relative stranger to her: “I could tell him off so, so.” Her emotional dialogue revealed how she recognised her own and others’ thoughts and feelings and sought to interpret their meanings within the context of her own biography (Denzin, 1984). In addition, she used her feelings to monitor her own and other people’s actions and make moral judgements about relational behaviour.

## Discussion

### *The capacity for imagination in people with dementia*

People with more advanced dementia and impaired speech can therefore convey meaning via their emotions. Notably, the views and feelings of those in the study manifested themselves via embodied forms such as body posture, eye patterns, facial expressions, tone of voice and laughter (Mayhew et al, 2001). Their emotional states were conveyed quite clearly (eg, joy or sadness) or, alternatively, much more subtly (eg, affection or discontent). As well as being sensitive to their own and other people’s emotions, there was evidence that they could still imagine other people’s feelings when they no longer had the ability to directly enquire about them and even when the latter were materially absent, that is, they demonstrated imaginative projection (Emirbayer and Mische, 1998).

Therefore, people with more advanced dementia have the capacity to interpret and discern the meaning of their own and other people’s emotions, albeit this is challenged by the illness. In addition, they use their emotions to understand their social worlds –

demonstrated either implicitly or explicitly. As they also have the power to move us via their emotional actions and thereby maintain interconnectedness (Hutto, 2002), it appears that they can demonstrate emotional reflexivity. Whereas language is assumed to be essential for reflexivity (Madhok, 2013), on the contrary, emotional reflexivity can be exercised even when speech is impaired.

However, as some of the people with dementia also expressed emotions such as joy or sadness that did not seem to be prompted by their social environment at that point in time – for example when there was no clear explanation for their laughter – this indicated that these emotions were memory based. In addition, it appeared that their inner *social* worlds substituted somewhat for a lack of ability for social interaction and a loss of social contact. Notably, people who lacked the capability for interaction nonetheless remained emotionally engaged in social relations via internal dialogue, which manifested itself in their speech or utterances. Burkitt (2012) suggested that memory is central to the agentic self and, indeed, memory was important in enabling the people with dementia in the present study who had very limited social and language skills to continue to maintain an inner social life. At the same time, however, since they retained some practical relational abilities and could demonstrate when they enjoyed social interaction, this indicated that severe memory loss is *not* a barrier to relational agency. However, memory loss can limit the ability to envisage future (particularly complex) alternatives.

### *Are people with dementia emotionally reflexive?*

People with more advanced dementia who lack deliberative agency (Emirbayer and Mische, 1998) can nonetheless use their emotions to exercise reflexivity and seek to influence their relationships. As Kimmel (2008) pointed out, emotional intimacy relies heavily on non-verbal communication of thoughts and feelings. While the people with more advanced dementia in the study had difficulty making everyday decisions, they could still use their emotions to inform and express their views and feelings on quite sophisticated issues, such as:

- their perceptions of strangers;
- social judgements of others;
- marital dynamics;
- sexual identity;
- religious beliefs.

In turn, their emotions were a response to their beliefs about the social world, for example relating to:

- societal conventions;
- social status;
- marital roles;
- ethical behaviour.

Moreover, since the ability to read other people's emotions requires acute judgement (Smith, 2002), they therefore demonstrated some capacity for reasoning. Although

their practical abilities were limited, they could still imagine social action and consider its implications, at least to a degree.

However, the idealisation of rationality in Cartesian dualism has led to emotions being devalued (Stocker, 2002). Likewise, when emotions such as anxiety, agitation and depression are exhibited by people with dementia, these are classified as neuropsychiatric symptoms (Finkel, 2000). In contrast, however, such emotions are reflections of how people respond psychologically to the illness and to the altered expectations and behaviours of others, especially when they cannot articulate their feelings. In particular, defining anger as inherent to the disease disregards when such expressions indicate adaptive responses to maladaptive environments. Fundamentally, the pathologisation of emotion in dementia is problematic because it assumes a priori that such expressions are indicative of brain pathology (Godfrey et al, 2005). Since dementia can be an overwhelming emotional experience, emotions may be heightened or numbed or there might be a loss of balance in emotion. However, such emotional responses are not confined to dementia but are intrinsic to human experience (Burkitt, 2014). Rather than being deemed a loss of rationality, emotions in dementia can be viewed as an experiential process of reasoning through the impact of the illness on one's sense of self and relations with others. Therefore, the emotion of people with dementia demonstrates reflexivity.

At the same time, however, we rely on others to discern and legitimate our emotions and to affirm our sense of self (Burkitt, 2008; Wetherell, 2012). Unfortunately, the emotions of people with dementia are not always recognised or validated (Boyle, 2008). Yet, attentiveness to their emotions is essential for recognising their agency, particularly when they lack speech. Rather than their emotions being indicative of disordered minds, they highlight when they are trying to make sense of their shifting social worlds. In addition, their emotions provide insight into their psychological and social wellbeing or ill-being, for example when participants in the study conveyed confinement, anxiety or a low opinion of self. Yet, since emotional experiences are 'co-created' (Wetherell, 2012), negative emotions can reflect how relational agency relies on the provision of social support – practical and emotional – which may not always be forthcoming or adequate. Indeed, while agency theory portrays relational agency as mutually supportive, on the contrary, social resources are often unequally distributed (Duncan, 2011).

### *Using emotion as a moral guide to social life*

The people with dementia in the study also used their interpretations of their own and other people's emotions to ethically inform their relationships. Even when they could not act practically on their own behalf – for example when they lacked the ability to undertake activities of daily living – and also lacked deliberative agency (that is, they were unable to make everyday decisions), they could still use their emotions to act ethically, at least to some degree. Relational dialogue is the means by which we take account of our own and other people's values and make moral judgements about our actions (Sullivan and McCarthy, 2004). Likewise, emotional reflexivity has a moral dimension whereby emotions are used to inform one's own ethical behaviour. Accordingly, people with more advanced dementia exhibited regard for others, for example when they showed warmth and kindness. In addition, they sought to ascertain other people's motivations and reward evidence of integrity, such as when they judged

us as researchers to be trustworthy and endeavoured to be helpful to us (Smart et al, 2012). They also demonstrated concern when the behaviour of others appeared to challenge their moral standards, for example when a husband was perceived to have been somewhat remiss. Irrespective of their advanced cognitive impairment, they used their emotional imagination to assert their moral identity (Denzin, 1984).

However, emotional relations can also involve dynamics of status and authority (Holmes, 2011). Accordingly, some people with dementia in the study conveyed a sense of ‘ontological insecurity’ – for example via their anxiety – particularly when they had limited ability to probe others about their actions (Smart et al, 2012). Indeed, within the overall study, spouses with dementia – particularly wives – evinced a degree of vulnerability about their increasingly dependent status within their marital relationships (Boyle, 2013). Similarly, Smart et al (2012) suggest that women are more likely than men to be open about their perceived vulnerability within relationships. Whereas dementia research often focuses on self-esteem as an internally derived form of self-conception, which becomes susceptible to the invasive effects of the illness (eg, Brod et al, 1999), of course social relations influence our *social* esteem (Honneth, 1995). Accordingly, a decline of self in dementia may result from the loss of recognition by others (Sabat and Harre, 1992). The sense of ‘ontological insecurity’ evident among some of the people with dementia in the study indicated that, while their understanding of their social lives was reduced, they were still conscious of subtle changes in relationship dynamics. Indeed, their ‘struggle for (relational) recognition’ (Honneth, 1995) was reflected in their emotionally agentic efforts to maintain their status within their intimate relationships.

## Conclusions

The predominant focus on awareness in cognitive psychology has led to the potential capacity for reflexivity in people with dementia being overlooked. Similarly, the adoption of a cognitive concept of ‘reflexivity’ in much agency debate excludes people with dementia. In contrast, the concept of ‘emotional reflexivity’ allows for people with dementia to convey feeling and reason, particularly when their abilities for deliberation, discourse and social interaction are limited. Therefore, future research into the lives of people with dementia should be broadened to identify when they can demonstrate reflexivity and relational agency, irrespective of their cognitive impairment. In addition, a shift in agency theory is needed from privileging rationality and language to recognising the value of *emotional* dialogue.

Whereas the emotions of people with more advanced dementia have often been reduced to biological sensations (Fontana and Smith, 1989), on the contrary, they point to the affective, imaginative and moral nature of their reflexivity. Indeed, since understanding of our own and other people’s feelings indicates consciousness (Denzin, 1984; Sullivan and McCarthy, 2004), it appears that people with more advanced dementia can demonstrate greater consciousness than has been assumed from awareness research. In addition, their capacity for imaginative agency suggests that their intersubjectivity can be preserved even when social skills are apparently lost. Moreover, since they retain an inner *social* life even when their ability to engage in the ‘real world’ is limited, this points to the adaptive potential of intersubjectivity more generally. As Burkitt (2014) states, emotions not only inform, but also constitute, patterns of social relations. However, as the present study did not include people



with severe dementia, subsequent research should determine whether they can also demonstrate emotional reflexivity.

As the loss of ability to act in people with dementia has often been conflated with the loss of the abilities to think and feel (eg, Collopy, 1995), this has also contributed to the reflexivity of people with dementia being unrecognised. More generally, since agency theory is rooted in a physical concept of 'social action' (Reader, 2007), this has led to the neglect of other forms of action, particularly emotion. As agency theory is therefore somewhat exclusionary of disabled people, a more inclusive and enabling concept of 'social action' is needed that allows for equal recognition of other forms of action (Baker et al, 2004).

It is important to note that, since emotions are dramatisations of feeling, they are difficult to capture by traditional social science methods and are poorly represented by academic language. Therefore, future research should further explore the value of using creative methods to capture emotional dialogue. Innovative methods such as the 'interaction' method used here are needed to explore the personal meanings conveyed by the emotions of people with dementia, particularly since current research is dominated by a structured observation methodology, which applies quantitative categorisations to emotion and behaviour (eg, Fossey et al, 2002).

## Note

<sup>1</sup> Pseudonyms are used throughout this article.

## References

- Aalten, P, Van Valen, E, Clare, L, Kenny, G, Verhey, F, 2005, Awareness in dementia: a review of clinical correlates, *Aging & Mental Health*, 9, 5, 414–22
- Acton, G, Yauk, S, Hopkins, B, Mayhew, P, 2007, Increasing social communication in persons with dementia, *Research and Theory for Nursing Practice: An International Journal*, 21, 1, 32–44
- Archer, M, 2003, *Structure, agency and the internal conversation*, Cambridge: Cambridge University Press
- Baker, J, Lynch, K, Cantillon, S, Walsh, J, 2004, *Equality: From theory to action*, Basingstoke: Palgrave Macmillan
- Boyle, G, 2008, Controlling behaviour using neuroleptic drugs: the role of the Mental Capacity Act 2005 in protecting the liberty of people with dementia, *Disability and Society*, 23, 7, 759–71
- Boyle, G, 2013a, Still a woman's job: the division of housework in couples living with dementia, *Families, Relationships & Societies*, 2, 1, 5–21
- Boyle, G, 2013b, 'She's usually quicker than the calculator': Financial management and decision-making in couples living with dementia, *Health and Social Care in the Community*, 21, 5, 554–62
- Boyle, G, 2013c, Facilitating decision-making by people with dementia: is spousal support gendered?, *Journal of Social Welfare and Family Law*, 35, 2, 227–243.
- Boyle, G, 2014a, 'Can't cook, won't cook': Men's involvement in cooking when their wives develop dementia, *Journal of Gender Studies*, 23, 4, 336–350.
- Boyle, G, 2014b, Recognising the agency of people with dementia, *Disability and Society*, 29, 7, 1130–44
- Brock, D, 1993, *Life and death: Philosophical essays in biomedical ethics*, Cambridge: University of Cambridge



- Brod, M, Stewart, A, Sands, L, Walton, P, 1999, Conceptualization and measurement of quality of life in dementia: the Dementia Quality of Life Instrument (DQoL), *The Gerontologist*, 39, 1, 25-35
- Burkitt, I, 2008, *Social selves: Theories of self and society* (2nd edn), London: Sage Publications
- Burkitt, I, 2012, Emotional reflexivity: feeling, emotion and imagination in reflexive dialogues, *Sociology*, 46, 458-72
- Burkitt, I, 2014, *Emotions and social relations*, London: Sage Publications
- Caddell, LS, Clare, L, 2010, The impact of dementia on self and identity: a systematic review, *Clinical Psychology Review*, 30, 113-26
- Clare, L, 2003, Managing threats to self: awareness in early stage Alzheimer's disease, *Social Science and Medicine*, 57, 6, 1017-29
- Clare, L, Markova, I, Roth, I, Morris, R, 2011, Awareness in Alzheimer's disease and associated dementias: theoretical framework and clinical implications, *Aging & Mental Health*, 15, 8, 936-44
- Clare, L, Rowlands, J, Bruce, E, Surr, C, Downs, M, 2008, 'I don't do like I used to do': a grounded theory approach to conceptualising awareness in people with moderate to severe dementia living in long-term care, *Social Science and Medicine*, 66, 2366-77
- Collopy, BJ, 1995, Power, paternalism and the ambiguities of autonomy, in L.M. Gamroth, J. Semradek and E.M. Tornquist (eds) *Enhancing autonomy in long-term care: Concepts and strategies*, New York, NY: Springer, 3-14
- Cooley, C, 1922, *Human nature and the social order* (2nd edn), London: Transaction
- Denzin, N, 1970, *The research act in sociology: A theoretical introduction to sociological methods*, London: Butterworth
- Denzin, N, 1984, *On understanding emotion*, London: Jossey-Bass
- Duncan, S, 2011, Personal life, pragmatism and bricolage, *Sociological Research Online*, 16, 4, 13, [www.socresonline.org.uk/16/4/13.html](http://www.socresonline.org.uk/16/4/13.html)
- Emirbayer, M, Mische, A, 1998, What is agency?, *American Journal of Sociology*, 103, 4, 962-1023
- Farrugia, D, 2013, Addressing the problem of reflexivity in theories of reflexive modernisation: subjectivity and structural contradiction, *Journal of Sociology*, doi: 10.1177/1440783313480396, 1-15
- Fields, J, Copp, M, Kleinman, S, 2006, Symbolic interactionism, inequality and emotions, in J. Stets and J. Turner (eds) *Handbook of the sociology of emotions*, New York, NY: Springer, 155-78
- Finkel, S, 2000, Introduction to Behavioural and Psychological Symptoms of Dementia (BPSD), *International Journal of Geriatric Psychiatry*, 15, supp 1, S2-S4
- Fontana, A, Smith, R, 1989, Alzheimer's disease victims: the 'unbecoming' of self and the normalization of competence, *Sociological Perspectives*, 32, 1, 35-46
- Fossey, J, Lee, L, Ballard, C, 2002, Dementia care mapping as a research tool for measuring quality of life in care settings: psychometric properties, *International Journal of Geriatric Psychiatry*, 17, 1064-70
- Giddens, A, 1984, *The constitution of society: Outline of the theory of structuration*, Cambridge: Polity Press
- Giddens, A, 1991, *Modernity and self-identity: Self and society in the late modern age*, Cambridge: Polity Press
- Godfrey, M, Surr, C, Boyle, G, Townsend, J, Brooker, D, 2005, *Prevention and service provision: Mental health problems in later life*, Leeds: University of Leeds

- Grove, N, Bunning, K, Porter, J, Olsson, C, 1999, See what I mean: interpreting the meaning of communication by people with severe and profound intellectual disabilities, *Journal of Applied Research in Intellectual Disabilities*, 12, 3, 190-203
- Hammersley, M, Atkinson, P, 2007, *What is ethnography? Ethnography, principles in practice* (3rd edn), New York, NY: Routledge
- Harper, D, 2002, Talking about pictures: a case for photo elicitation, *Visual Studies*, 17, 13-26
- Hemmings, C, Treacher Kabesh, A, 2013, The feminist subject of agency: recognition and affect in encounters with the 'other', in S. Madhok, A. Phillips and K. Wilson (eds) *Gender, agency and coercion*, London: Palgrave Macmillan, 29-46
- Holmes, M, 2004, An equal distance? Individualisation, gender and intimacy in distance relationships, *The Sociological Review*, 52, 2, 180-200
- Holmes, M, 2010, The emotionalization of reflexivity, *Sociology*, 44, 1, 139-54
- Holmes, M, 2011, Emotional reflexivity in contemporary friendships: understanding it using Elias and Facebook etiquette, *Sociological Research Online* 16, 1, 11, [www.socresonline.org.uk/16/1/11.html](http://www.socresonline.org.uk/16/1/11.html)
- Honneth, A, 1995, *The struggle for recognition: The moral grammar of social conflicts*, Cambridge: Polity Press
- Hughes, C, Berg, L, Danziger, W, Coben, L, Martin, R, 1982, A new clinical scale for the staging of dementia, *British Journal of Psychiatry*, 140, 566-72
- Hutto, D, 2002, The world is not enough: shared emotions and other minds, in P. Goldie (ed) *Understanding emotions: Mind and morals*, Aldershot: Ashgate, 37-53
- Kimmel, M (ed), 2008, *The gendered society*, Oxford: Oxford University Press
- Kitzinger, C, 2000, Doing feminist conversation analysis, *Feminism & Psychology*, 10, 163-93
- Kontos, PC, 2004, Ethnographic reflections on selfhood, embodiment and Alzheimer's disease, *Ageing & Society*, 24, 6, 829-49
- Langdon, SA, Eagle, A, Warner, J, 2007, Making sense of dementia in the social world: a qualitative study, *Social Science & Medicine*, 64, 979-1000
- Mackenzie, C, Stoljar, N, 2000, Introduction: refiguring autonomy, in C. Mackenzie and N. Stoljar (eds) *Relational autonomy: Feminist perspectives on autonomy, agency and the social self*, Oxford: Oxford University Press, 3-34
- Madhok, S, 2013, Action, agency, coercion: reformatting agency for oppressive contexts, in S. Madhok, A. Phillips and K. Wilson (eds) *Gender, agency and coercion*, London: Palgrave Macmillan, 102-21
- Madhok, S, Phillips, A, Wilson, K, 2013, Introduction, in S. Madhok, A. Phillips and K. Wilson (eds) *Gender, agency and coercion*, London: Palgrave Macmillan, 1-13
- Marin, D, Flynn, S, Mare, M, Lantz, M, Hsu, M, Laurans, M, Paredes, M. et al, 2001, Reliability and validity of a chronic care facility adaptation of the Clinical Dementia Rating Scale, *International Journal of Geriatric Psychiatry*, 16, 8, 745-50
- Mason, J, Dale, A, 2011, Creative tensions in social research: questions of method' in J. Mason and A. Dale (eds) *Understanding social research: Thinking creatively about method*, London: Sage Publications, 1-26
- Mayhew, PA, Acton, GJ, Yauk, S, Hopkins, BA, 2001, Communication from individuals with advanced DAT: an it provide clues to their sense of self-awareness and well-being?, *Geriatric Nursing*, 22, 2, 106-10
- Mental Capacity Act 2005*, London: HMSO.

- Miesen, B, 1992, Attachment theory and dementia, in G. Jones and B. Miesen (eds) *Caregiving in dementia*, London: Routledge, 38–56
- Miesen, B, Jones, G, 2004, The Alzheimer cafe concept: a response to the trauma, drama and tragedy of dementia, in G. Jones and B. Miesen (eds) *Caregiving in dementia*, London: Routledge, 307–33
- Nystrom, K, Lauritzen, S, 2005, Expressive bodies: demented persons' communication in a dance therapy context, *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine*, 9, 3, 297–17
- O'Cathain, A, 2010, Mixed methods involving qualitative research, in I. Bourgeault, R. Dingwall and R. deVries (eds) *The Sage publications handbook of qualitative methods in health research*, London: Sage Publications, 575–88
- Reader, S, 2007, The other side of agency, *Philosophy*, 82, 579–604
- Robinson, L, Clare, L, Evans, K, 2005, Making sense of dementia and adjusting to loss: psychological reactions to a diagnosis of dementia in couples, *Aging & Mental Health*, 9, 4, 337–47
- Sabat, S, 2002, Surviving manifestations of selfhood in Alzheimer's disease, *Dementia*, 1, 1, 25–36
- Sabat, S, Harre, R, 1992, The construction and deconstruction of self in Alzheimer's disease, *Ageing and Society*, 12, 443–61
- Small, J, Geldart, K, Gutman, G, Clarke Scott, M, 1998, The discourse of self in dementia, *Ageing and Society*, 18, 291–316
- Smart, C, Davies, K, Heaphy, B, Mason, J, 2012, Difficult friendships and ontological security, *The Sociological Review*, 60, 1, 91–109
- Smith, B, 2002, Keeping emotions in mind, in P. Goldie (ed) *Understanding emotions: Mind and morals*, Aldershot: Ashgate, 111–22
- Stocker, M, 2002, Some ways to evaluate emotions, in P. Goldie (ed) *Understanding emotions: Mind and morals*, Aldershot: Ashgate, 65–80
- Sugarman, J, Martin, J, 2011, Theorising relational agency, *Journal of Constructivist Psychology*, 24, 283–9
- Sullivan, P, 2012, *Qualitative data analysis: Using a dialogical approach*, London: Sage Publications
- Sullivan, P, McCarthy, J, 2004, Toward a dialogical perspective on agency, *Journal for the Theory of Social Behaviour*, 34, 3, 291–309
- Velleman, D, 2000, *The possibility of practical reason*, Oxford: Clarendon Press
- Wetherell, M, 2012, *Affect and emotion: A new social science understanding*, London: Sage Publications
- Woods, B, Pratt, R, 2005, Awareness in dementia: ethical and legal issues in relation to people with dementia, *Aging & Mental Health*, 9, 5, 423–9